GUIDELINES IN HANDLING A REPORT OF POSSIBLE MEDICAL NEGLECT OF A DISABLED INFANT (BABY DOE

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I. OVERVIEW

FEDERAL REGULATION

Federal regulations relating to the provisions of the Child Abuse Amendments of 1984 governing the protection and care of disabled infants are at 45 Code of Federal Regulations (CFR) Part 1340. These regulations require that states establish programs and/or procedures within their child protective service (CPS) system to respond to reports of "medical neglect, including instances of withholding of medically indicated treatment from disabled infants with life-threatening conditions" (commonly known as "Baby Doe").

RELATED WISCONSIN STATUTES

Wisconsin Statutes. 48.981(1)(d) defines neglect as failure, refusal or inability on the part of a parent, guardian, legal custodian or other person exercising temporary or permanent control over a child, for reasons other than poverty, to provide necessary care, food, clothing, medical or dental care or shelter so as to seriously endanger the physical health of the child." This definition extends protection to all children under the age of 18, both able-bodied and disabled, who are alleged to be neglected medically. Infants with disabilities, like all other children in Wisconsin, are extended the protection of s. 48.981 and related statutes. Reportable conditions for all children include:

Physical abuse;
Sexual abuse, exploitation or prostitution;
Emotional damage;
Neglect;
Threat of physical abuse;
Threat of sexual abuse, exploitation or prostitution;
Threat of neglect; or
Threat of emotional damage.

(Complete definitions ins. 48.981(1) Wisconsin Statutes)

Under state child abuse statutes, certain individuals whose employment brings them into contact with children are required to report suspected abuse or neglect they see in their professional role. Health care providers are required to report instances of suspected medical neglect of disabled infants.

In addition, Wisconsin Statute s. 146.82(2)(a)11 provides CPS with the capability to access medical records for the purpose of investigating suspected child abuse or neglect.

BACKGROUND FOR STATE BABY DOE GUIDELINES

All states receiving child abuse and neglect funds from the federal government must have procedures for handling a report of possible medical neglect of an infant in place. The Wisconsin Department of Health and Family Services receives a federal grant which is administered by the Division of Children and Family Services' Bureau of Program and Policies. A Baby Doe project was initiated in 1986 to establish the Guidelines for Handling a Report of Possible Medical Neglect of a Disabled Infant and to provide related information and education statewide.

In 1988, in accordance with federal law and Wisconsin state procedures each of the approximately 136 Wisconsin hospitals providing obstetrical and/or newborn care designated a staff person who is called the Baby Doe Hospital Designee, as detailed in Appendix 1. The hospital designee provides coordination for CPS activity and consultation to CPS staff during a Baby Doe investigation. In addition, this person has a responsibility to report to the county CPS agency instances of medical neglect of a disabled infant that come to his/her attention. The reporting responsibility of the hospital designee does not diminish the responsibility of persons required under Wisconsin law to report child abuse and neglect (s. 48.981(2)).

In Wisconsin, child protective services are provided by the 72 county social or human services agencies. The county agency as the investigating agency will conduct a diligent investigation in accordance with the Child Protective Service Investigation Standards developed by the Department in accordance with 48.981(3)(c).

The following document is intended to assist child protective service workers, health care providers, legal counsel, and the court system in broadening their understanding of, and defining roles and responsibilities in handling Baby Doe situations. These guidelines should be seen as a supplement to the Child Protective Services Investigation Standards issued September 1, 1994 to address the special practice considerations for responding to a report of this nature. (See "Child Protective Services (CPS) procedures for Responding to a Baby Doe Report," p.14 of this document.)

USING THESE GUIDELINES

It is mandated by the federal Baby Doe regulation that "programs or procedures" be in place in states for the use of child protective services agencies in responding to a report of possible medical neglect of a disabled infant. These guidelines serve, in part, to outline CPS procedures. It does place some requirements on the policies of medical neglect, coordination and notification requirements.

45 CFR 1340.15(c) does require "program, procedures or both" to be in place for funding. Because the two professional entities, child protective services and health care services, interact so closely during a Baby Doe investigation, these procedures are offered as guidelines to both groups.

It is suggested that each of the Wisconsin counties and those hospitals providing obstetrical and/or newborn care review these guidelines periodically with an eye to adding to them in ways that may make them more applicable to specific local situations. It is also suggested that county agencies and hospitals within those counties meet with each other periodically for mutual identification, discussion of complex issues, and preplanning. Preplanning, prior to the intensity of an actual case, can be of great mutual benefit.

Further, it is advisable for counties and hospitals to seek the advice and support of their own legal counsel on the multitude of complex issues that Baby Doe cases encompass. Although there is little case law in this area, it is wise to request that the agency's legal counsel become as informed as possible and that discussion take place between the agency and the legal counsel prior to as well as during an actual case situation.

It is important to state at the outset that Baby Doe cases may be difficult to resolve and are rarely clear cut. Past situations have shown that each case arouses community sentiment and influences public policy in one direction or another. Therefore, conscientious professional behavior by all involved is of great importance.

DEFINITIONS FROM FEDERAL REGULATION - (See 45 CFR Part 1340)

1. The term "medical neglect" means the failure to provide adequate medical care, and includes, but is not limited to, the withholding of medically indicated treatment from a disabled infant with a life-threatening condition.

2. The term "withholding of medically indicated treatment" means the failure to respond to the infant's life threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's (or physicians') reasonable medical judgement, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition,, hydration, or medication) to an infant when, in the treating physician's (or physicians') reasonable medical judgement any of the following circumstances apply:

    a. The infant is chronically and irreversibly comatose;

    b. The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or

    c. The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

3. The term "infant" means an infant less than one year of age. The reference to less than one year of age shall not be construed to imply that treatment should by changed or discontinued when an infant reaches one year of age, or to affect or limit any existing protections available under State laws regarding medical neglect of children over one year of age. In addition to their applicability to infants less than one year of age, the standards set forth above should be consulted thoroughly in the evaluation of any issue of medical neglect involving an infant older than one year of age who has been continuously hospitalized since birth, who was born extremely prematurely, or who has a long-term disability.

4. The term "reasonable medical judgement" means a medical judgement that would by made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved.

5. The term "hospital designee" means a person(s) who is designated by an administrator of each hospital that provides obstetrical and/or newborn services in the state. The designee's role is to promptly notify CPS of cases of suspected medical neglect that come to the designee's attention. The designee is also to provide coordination and consultation to CPS within the health care facility during a Baby Doe investigation.

PERINATAL SYSTEM IN WISCONSIN

Wisconsin has become known nationally in the last 20 years as being in the forefront of the movement to provide neonatal intensive care in a regionalized perinatal system. This has meant that regionalized perinatal care is available to all residents and that specialized procedures and expertise are available to meet the needs of disabled, genetically impaired, birth-damaged, pre-term, low birth weight, and other at-risk infants.

Wisconsin has 11 perinatal centers with neonatal intensive care units staffed by neonatologists and neonatal nurses (physicians and nurses who specialize in the treatment of pre-term, ill, and disabled newborns) and with perinatal social workers available to provide support and information to families. These centers are located in six counties. (See map and list of perinatal centers in Appendices 3 and 4.) Each of these centers has ready access to consultation from a variety of specialists who are experienced in the treatment of various disabilities. Genetics consultation is also available and can assist in arriving at an accurate diagnosis. In addition, each center provides outreach education, referral, and consultation to other hospitals in the perinatal region that specialize in lower-risk obstetrical and newborn services.

In some instances, if it is known or suspected prior to birth that an infant is going to have a medical problem, the attending physician may recommend to the family that delivery occur at a perinatal center so that expertise and resources are close at hand. In other instances, telephone consultation to the perinatal center will be initiated by the local physician and/or the baby will be transported to the perinatal center after birth. If a baby is in a perinatal center, it-is highly likely that medical consultation will be sought from geneticists and/or specialists in the disability that the baby possesses.

NEEDS OF FAMILIES

It is imperative that both child protective service workers and health care providers in anticipating how to handle a Baby Doe situation to be acutely aware of the needs of families. The birth of a disabled, pre-term, genetically impaired, or at risk infant can be a devastating event to parents. To be suddenly caught up in a situation of uncertainty, confusion, and unexpected decision-making greatly compounds the family's stress. There is, however, a great need to encourage as close physical and emotional contact between parent(s) and infant as is possible in order to foster the development of commitment and relationship, no matter what the infant's prognosis or ultimate course of treatment.

Priority areas for those working with families should be support for the development of an emotional bond between infant, parent(s) and other family members; sensitivity to individual perceptions and value systems; and respect for family privacy. Efforts need to be made to shield parents from additional stress.

Child protective service workers and health care providers should start with the assumption that parents are loving and concerned guardians of their children and that their needs, feelings, and rights as parents should command utmost respect.

RIGHTS OF INFANTS

The Baby Doe legislation attempts to address two areas related to the rights of infants. A few words about these areas, parental guardianship and attitudes toward disability, may serve to clarify understanding about the context in which the current Baby Doe discussion takes place.

At different points in history, the status of infants, and indeed all children, has been seen, both socially and legally, from various perspectives. Parents have traditionally had the legal right and obligation as well as the personal insight, concern, and love to make decisions regarding the health and welfare of their children. In the vast majority of instances, parents are the most enlightened and thoughtful decision-makers for their children. Government's role, however, is to protect children from abuse or neglect by parents or others. In this role, government recognizes that children have rights of their own to. be protected, independent of the guardianship that parents maintain in relation to their children and above and beyond the needs and desires of the parents. In Baby Doe cases, one of the tensions that may exist is between the rights of parents as guardians to protect and make wise decisions on behalf of their children and the rights of children to be protected as individuals by the government.

A second issue pertaining to the rights of infants that may pervade Baby Doe cases has to do with attitudes toward disability. There have been times when disabled children have been devalued by their families or physicians, in part perhaps, because there was not the medical technology available to help these children. The few highly publicized Baby Doe cases in the early 1980's dealt with decisions not to provide lifesaving medical treatment to infants because they were born with a major disability. Although there were many examples of appropriate medical treatment being provided to disabled infants, the Baby Doe legislation came into being to prevent discriminatory non-treatment of infants born with disabilities. The law asserts that all infants have certain rights to medical treatment whether they are born in perfect condition or with a disability. Many current sources, both statewide and nationally, suggest that both disabled and pre-term infants are receiving needed medical treatment, and the prolonged treatment is becoming increasingly prevalent.

MEDICAL TECHNOLOGY

The rapid advancement of medical technology in the last few years has altered the traditional guidelines by which medical treatment decisions are made. In neonatal medicine, infants, for whom there was little question about survivability in the recent past, can now be kept alive and, in some cases, treated with favorable prognosis. However, the capacity to assist more infants to stay alive and even thrive has also meant that some infants may become harmed or further damaged in the process of attempting to help them. The standard of doing what is in the "best interest of the child" has, in some instances, become blurred in the face of medical technology that has the increasing capacity to keep infants alive indefinitely.

ETHICS COMMITTEES

In a 1983 report, the President's Commission for the Study of Ethical Problems in Medicine strongly encouraged and provided guidelines for the establishment of ethics committees to review cases in which the benefits of treatment for seriously ill newborns are not clear-cut. Since that time, a number of courts, legislatures, and professional organizations (including the American Academy of Pediatrics) have endorsed the value of ethics committees in addressing dilemmas surrounding treatment of impaired infants. Ethics committees, which are most often comprised of a cross section of professional and community people, can help institutions address such dilemmas through three activities. Ethics committees can:

- Develop and present educational seminars on neonatal decision-making for staff, parents, families, and the community;
- Develop policies concerning neonatal decision-making;
- Provide advice in individual cases involving impaired infants.

In their case consultation role, ethics committees carefully review information pertaining to complex medical/ethical cases with the attending and consulting physicians, nursing staff, family members, and other concerned persons. The multi-disciplinary committee members share their own expertise and experiences regarding the issues presented, and often, through group consensus, an advisory opinion results. The commitment of the ethics committee is to a multi-disciplinary, group process approach in which facts of the case are thoroughly explored and the varied expertise and perspectives of the committee members can be brought to bear in making momentous life and death decisions. Through this process:

- questions about the patient's condition and alternative treatment approaches can be expressed by people who have concerns,
- information can be presented simultaneously to all concerned individuals,
- information that is sketchy or unclear can be highlighted and further data gathered,
- discussion among people with different expertise, experiences, perspectives and values can take place, and
- support for carefully considered treatment decisions can be given.

In Wisconsin, most hospitals have hospital-wide ethics committees which provide consultation in cases involving patients of all ages--including newborns. In the near future it is anticipated that all of the state's hospitals will have ethics committees capable of providing consultation regarding treatment of impaired infants. Ethics committees can help satisfy the most recent guidelines of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), which require institutions to have mechanisms for addressing ethical issues in patient care, resolving conflict, and providing medical ethics education for patients and health care providers.

The Wisconsin Ethics Committee Network (WECN) was established in 1987 by the Center for the Study of Bioethics, Medical College of Wisconsin, with a grant from the Wisconsin Baby Doe Project, to develop and improve the functioning of Wisconsin's institutional ethics committees. WECN membership includes over 100 hospitals, long-term care facilities, home health agencies, professional organizations, legislators, social service organizations, legislators, social service organizations, community groups and interested individuals. WECN's educational, research, consultative and policy-making accomplishments since its inception include: publication and dissemination of "Resources for Wisconsin Ethics Committees," an anthology of landmark bioethics articles; publication of the WECN "Pediatric Ethics Anthology, " a collection of key pediatrics ethics articles; establishment of a statewide Speaker's Bureau; compilation of sample institutional policies relating to ethical issues in health care; delivery of consultative services to member institutions throughout the state; sponsorship of outstanding educational programs featuring local, state, national, and international experts in medical ethics; establishment of a health policy discussion group for the exchange of ideas between WECN members and state legislators; research on characteristics and functioning of ethics committees throughout the state; and guidance in forming new and enhancing the functioning of existing ethics committees. Access to the Medical College of Wisconsin's Bioethics Online Service, a computerized database offering abstracts of medical ethics articles, current legal decisions, news and announcements, and a special WECN Bioethics Online Discussion Forum, is one of the newest services offered to institutional members of the Network. The Discussion Forum feature of the Online Service will provide hospital ethics committees with rapid access to consultation services for difficult cases, including those involving treatment of impaired newborns.

While ethics committees are not required by either federal or state law, experience has shown that such committees can be very helpful in analyzing and resolving difficult cases involving impaired infants. This is particularly true when there is initial disagreement about the course of treatment among health care team members, among family members, or between family members and the health care team. The ethics committee's thorough review of the medical facts, its facilitation of discussion among concerned individuals, and its multidisciplinary advisory opinion should be viewed as important contributions to the overall decision-making process in a Baby Doe case.

INTERDISCIPLINARY COOPERATION

Cooperative interaction among the various professionals involved in a Baby Doe case is a primary goal. Meeting and planning together before being faced with an actual case can be of great mutual benefit. The following suggestions are made:

- Be aware of who the hospital designees and the CPS personnel are in the county. (Refer to the directories of each published.)
- Be aware of the resources available through the Wisconsin Ethics Committee Network (WECN). (See information on WECN on Page 10.)
- Attempt to establish mutually respectful relationships among health care providers, child protective services personnel, and the court system.
- Become aware of each other's concerns and dilemmas in anticipating a possible Baby Doe case.
- Be responsive to the idea of cooperative preplanning and mutual in-service training among child protective services, health care providers, legal services, and the court system.
- Be familiar with federal and state laws regarding medical neglect of disabled infants.
- Be familiar with the community service delivery system for disabled infants and their families. Make preliminary contacts with parent support/advocacy groups that could provide assistance to parents as needed.
- Review existing procedures within the county for gaining immediate access to the court system in order to determine expedient procedures for use in Baby Doe cases.

SUGGESTED RESPONSIBILITIES OF PHYSICIANS/NURSES/HOSPITALS IN ANTICIPATING THE POSSIBILITY OF A BABY DOE CASE

- Be familiar with neonatal resources and genetic consultation available in the region and/or state. Be aware of specialists with expertise in various neonatal conditions who are knowledgeable about the treatment possibilities with respect to these conditions. Maintain channels of communication, referral and consultation.

- Be knowledgeable about the benefits and functions of ethics committees in addressing complex treatment decisions. Consider establishing an ethics committee (following professional organization guidelines) or having provision for ethics committee consultation. Establish guidelines about when to contact an ethics committee regarding infant boiethical issues.

- Be knowledgeable about the state child abuse and neglect reporting requirements of medical personnel.

- Be aware of services and programs in the community available to infants with disabilities and to their families.

- Designate an appropriate person, called a Baby Doe hospital designee, to report cases of possible medical neglect of disabled infants to CPS and to provide coordination and consultation between the hospital and CPS during an investigation. (See Appendix 1 - Responsibilities of Baby Doe Hospital Designee.)

- Resuscitate, support, and/or treat any live-born infant until further diagnostic decisions can be made or additional consultation can be sought.

- During a Baby Doe investigation, attempt to keep the infant in a stabilized condition and prevent deterioration or further damage. Provide appropriate nutrition, hydration, medication, and medical treatment.

- During a Baby Doe investigation, provide information and support to the infants' parent(s) so they can be as informed participants as possible. Promote physical and emotional contact between parent(s), infant, and other significant family members to encourage relationship development.

- During a Baby Doe investigation, cooperate fully with the CPS worker, agency, and investigation. Make medical records available in accordance with Wisconsin law.

II. CHILD PROTECTIVE SERVICE (CPS) PROCEDURES FOR RESPONDING TO A BABY DOE REPORT

The child protective services (CPS) system should be the first avenue in pursuing a report of abuse or neglect of a child, including possible medical neglect of a disabled infant. Although the judicial system is always available in cases of verifiable neglect, a CPS investigation should utilize all avenues of fact-finding, information sharing, clarification seeking, services provision, and mediation in order to attempt an informal, nonjudicial resolution.

In brief, a CPS investigation of a Baby Doe report consists of following the Child Protective Services Investigation Standards for "Maltreatment by Parents". The unique circumstances of a Baby Doe report dictate certain modifications to the standard for "Maltreatment by Parents". Such modifications to the "Maltreatment by Parents" Standard are in *italics* below. Please note that certain directions for the Standard for "Maltreatment by Parents" may be deleted for the exception below. This is for the purpose of tailoring the investigation to the unique circumstances for responding to a report of suspected medical neglect of a disabled infant.

PROCEDURES FOR RESPONDING TO A REPORT OF SUSPECTED MEDICAL NEGLECT OF A DISABLED INFANT

PURPOSE

In responding to reports of possible medical neglect of a disabled infant (BABY DOE), Child Protective Service (CPS) represents a community concern to assess for medical neglect of infants born with disabilities. At investigation, the CPS purpose is to:

- assess the current safety of *the disabled infant;*
- assess the family's need for services;
- introduce the agency as a provider of help; and
- if warranted, take action to control circumstances jeopardizing child safety.

Who are "Parents"?

For the purpose of the Standard, parents are birth, adoptive or stepparents and the child's guardian or legal custodian. This Standard will use "parent" in referring to any of these individuals.

Collaboration

These investigations should also involve hospital medical personnel and/or hospital ethics committees to acquire medical information, data, or records as needed. These Guidelines recommend that hospitals appoint a designee to collaborate with CPS in handling a report of possible medical neglect of a disabled infant. These investigations should also involve law enforcement personnel, as dictated by the county agency's interagency agreements. It is the role of law enforcement staff to collect evidence related to possible criminal behavior.

Decisions for Intake

The following decisions and supporting rationale must by documented in the record:

- Is this an appropriate child protective service referral? If a report is screened out, documentation and the basis for the decision must be maintained.
- What is the agency's time frame for contact with principals of the report *or with medical personnel?*
- *Are immediate actions necessary to keep the child alive?*

Immediate Responsibility

A report of possible medical neglect of a disabled infant needs to be analyzed for urgency immediately. Within the first 24 hours of receiving a report of possible medical neglect of a disabled infant, agency staff must, at a minimum, take the following action:

- Gather the following information, if available, from the reporter or from hospital medical personnel:

    A. Description of the alleged medical neglect and circumstances

    B. Description of the child, *highlighting current life or health-threatening problem requiring treatment*

    C. Description of the parents, *including actions or response by parents to their infant's life threatening condition*

    D. Description of the family, current stresses, and how the family might respond to intervention or treatment for the child

    E. Description of any action taken or recommended by hospital medical personnel

    F. All household members' names and relationships, ages, addresses, phone numbers, and places of employment

    G. Reporter's name, relationship to the family, motivation and source of information, if possible

    H. Other *people/medical personnel* with information

- The information must be analyzed to assess urgency for response. At a minimum, the following must be considered:

    A. Child's medical condition, life threatening or health threatening problem requiring treatment.

    B. Have the parents refused consent to life sustaining treatment?

    C. Are immediate actions necessary to keep the child alive and stabilized?

    D. Any actions, taken or recommended by hospital medical personnel or the parents in response to the infant's life threatening condition. Specifically consider the following:

        - *Whether life sustaining treatment is recommended or implemented.*

        - *Whether the hospital will sustain life-supporting care for the immediate future while the CPS investigation is underway.*

        - *Whether sustenance (food or water, either given orally or through an intravenous or nasogastric tube) will be provided or denied for the immediate future? if denied, on what basis?*

The time frame for initial contact must be based on this analysis. Urgent cases require an immediate response. Collateral contacts may be indicated at intake to facilitate appropriate decision-making by the agency. If sufficient information is not available at intake, the case must be assigned a more prompt response. All cases must receive an initial face to face contact within five working days. A time frame for response within these parameters must be determined by or approved by a supervisor.

Document all activities related to screening and urgency, as described above.

Supervisor signature indicating approval of process and decision-making.

Decisions to be Made in the Course of Investigation

The following decisions and supporting rationale must be documented in the record, based on the information gathered during investigation:

- *Is the allegation of medical neglect substantiated?*

- *Is treatment medically indicated or not?*

- *If not, document, who, if anyone, has concluded that:*

    - *The child is irreversibly and chronically comatose.*

    - *The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life threatening condition, or otherwise be futile in terms of the survival of the infant, or the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.*

- *If treatment and care is indicated, are there circumstances suggesting that the parents will not follow through with needed care?*

- *Will the case be opened for ongoing service?*

The appropriate care of the infant must be ensured at all times while the information gathering is being accomplished. Informal resolution of the situation should be sought at every stage. However, if this is not possible, CPS has the authority understate law to seek judicial involvement.

Interview Protocol

Practical considerations in a report of possible medical neglect dictate variation from the recommended interviewing protocol for maltreatment by parents. Usually the infant is hospitalized at the time of a report and the parents may be in great distress to learn of their infant's disability and life threatening condition. It is recommended that CPS begin their investigation with a contact to the hospital Baby Doe designee to begin information gathering about the child and family situation. The designee is the primary coordinator and facilitator of the agency's CPS activities within the hospital. The order in which interviews take place should consider preserving information and minimizing the trauma for parents who are in the process of learning about the nature of their child's life threatening condition. By statute, the investigation must include face to face contact with the infant and parents. By statute, if the parent(s) alleged to be medically neglecting the child shares a home with that child, the investigation must include a visit to the home. Generally, it would not be practical or necessary to interview siblings for a report of possible medical neglect of a disabled infant. In all instances the hospital facility staff should be contacted so that all internal actions related to the alleged maltreatment can be reviewed. The date, time and circumstances of each interview should be documented in the record.

Interview Content

Thorough information should be gathered on the following, at a minimum:

A. The child's *condition,* ascertain how urgent the situation is in terms of life threat and stabilization and prevention of deterioration or further damage.

B. The parents' individual functioning and parenting practices

C. The family's functioning, strengths and current stresses

D. How the family responds to intervention

E. Response on the part of involved medical personnel or hospital facility (include information on Ethics Committee Reports, if an ethics committee has reviewed the medical condition of the child). Seek verification from the designee that all efforts are being made to maintain the infant in a stabilized condition during the course of the investigation, including necessary nutrition, hydration, and medication.

Interview content must be documented in the record.

Completion of the Investigation

The investigation must be completed within sixty days of the receipt of the report. At completion of the investigation, the record must contain:

- Documentation of all decisions and information gathering, as described above
- Documentation of closure with the family, including discussion of the results of the investigation and decisions regarding ongoing service provision and referral if appropriate
- Documentation of feedback to the mandated reporter, if applicable
- DCS-40 form
- Supervisor signature indicating approval of the process and decision making.

ADDITIONAL PRACTICE CONSIDERATIONS FOR CPS

1. Baby Doe cases are to be reported to the county in which the hospital where the infant as a patient, is located. If the infant is going to be transferred, e.g., to a perinatal center in another county, the report also goes to the county where the perinatal center is located. However, every effort should be made to keep the county where the infant's parents reside informed of the events. That county will be responsible for ongoing service to the family when the baby goes home and will have financial responsibilities if the baby requires alternative care in the home county. Close communication and an across-county-lines team effort should be fostered.
2. As soon as preliminary intake information has been obtained from the hospital designee, the worker and/or supervisor should consider organizing an internal county agency staffing to develop a plan for proceeding with the investigation protocol and to anticipate what may be ahead. The ground work laid in this meeting should provide support and direction to the worker designated as responsible for the overall coordination of the case. Worker and supervisor should, of course, maintain close contact during activity in the case and should arrange additional staffings or consultations as needed.
3. The worker assigned the case should contact the Baby Doe designee at the hospital where the baby is a patient as a first step in the investigative process, unless the designee is also the reporter and therefore already aware of the situation. The designee is usually the worker's first contact and the primary coordinator and facilitator of the worker's activities within the hospital.
4. The worker should obtain a current status report on the infant from the hospital designee. It is important to understand quickly where the infant is on the health status continuum from immediate questionable survivability to longer term dysfunction. Ascertain how urgent the situation is in terms of life threat stabilized condition and prevention of deterioration or further damage. Seek verification from the designee that all efforts are being made to maintain the infant in a stabilized condition during the course of the investigation, including providing necessary nutrition, hydration and medication.
5. In planning for contact with parent(s), request information on the status of the infant's parent(s) and with the designee, formulate a plan for telling the family of the investigation and involving them in the process. The worker may first envision playing a facilitative or behind the scenes advocacy role to ensure that the family has adequate support and that the parent(s) have information provided to them. The hospital social worker may be of assistance in determining the person in the health care setting with whom the parents are most comfortable. The maintenance of this relationship as a primary one to the parents is crucial. An important goal of this one-to-one relationship is to minimize alienation of the parent(s) from the system.

   Be sensitive to the trauma the infant's family is experiencing and assess the needs of all family members. Encourage ongoing contact between parent and other significant family members.
6. In talking with parents directly to ascertain their understanding of what is going on, be aware that two factors may be operating. First, there may be a gap in communication and sophistication between parents and the health care team. Health care personnel may believe that they have explained

things thoroughly and simply, parents may have appeared to comprehend, but on further review with parents it may become apparent that they are not really informed participants. Second, parents may not be able psychologically to hear and absorb what is being said because of their own pain, distress; and confusion. Parents who have been in such a situation speak of being numb, bewildered, and unable to think, comprehend, or formulate questions. Parents have said that it was important to have the issues faced by them and their infant continually rediscussed and that it was helpful to have the relative importance of decisions and time frames highlighted for them. Both the hospital support person and the outside support person can be helpful in these ways.

7. With the designee, ascertain who are the major participants on the health care team and what their positions are regarding the current treatment plan. Ask the designee to inform the health care team that a report of possible medical neglect has been made and an investigation is in process, if they are not already aware of this.

8. Discuss with the designee the possible need for access to medical records and request that the designee make preparations to obtain these. It is assumed that a physician, nurse, or social worker within the health care setting will be available to assist the worker, as needed, in summarizing, interpreting, and answering technical questions about material that appears in the infant's medical chart.

9. If upon notification that a Baby Doe report has been made, the hospital initiates an internal review of the case (including ethics committee meeting and/or seeking additional medical consultation) or if the worker discovers that an internal hospital review of the case in question is already in process, the worker should attempt to dovetail the CPS investigation with the hospital review, with the hope of using the information obtained in the review to assist in resolving the situation. The worker should consider playing a close-observer role during the internal hospital review, provided the worker can ensure that the infant is being maintained during this time and that the internal review is proceeding expeditiously.

10. If the hospital has an ethics committee or a plan for ethics committee consultation, ask the designee to inform the ethics committee chair of the Baby Doe report and investigation. The relationship and interaction between the CPS investigative process and the ethics committee review process are significant. In general, the more multidisciplinary the CPS investigation can become, the greater the chance for engaging in a thorough review and creating a thoughtful decision-making environment. Typically, a report from an ethics committee would be viewed as an important piece in the decision-making puzzle.

    If the ethics committee has not met at the time that the CPS worker enters the picture, a request should be made that the ethics committee meet and permission requested to observe the ethics committee meeting. Although responses to the request to be present at such a meeting may vary between hospital, the worker should attempt to play as interactive a role as possible with the ethics committee. The worker may want to talk with the committee chair to explain the reasons for involvement - chiefly, that the worker shares a common goal with the committee in expeditiously seeking to acquire information-factual emotional, and perceptual.

If the ethics committee has met prior to the CPS worker's involvement in the case, the worker should attempt to understand the process that the ethics committee went through as well as to review the final report. This could be done by reviewing a taped manuscript, if available, or by interviewing members of the committee. In this situation, it is important for the worker to understand the completeness, thoroughness, fairness and appropriateness of the ethics committee action in ascertaining the significance of the ethics committee report to the CPS investigative process.

11. If the infant is not in one of the region's perinatal centers, discuss with the designee if transfer has been considered. Ascertain if telephone consultation has been initiated between the local treating physician and a neonatologist at the regional center or other consultants elsewhere.

12. If a determination regarding the treatment questions cannot be reached and the infant is not in a perinatal center, the CPS worker may choose to seek advice from a neonatologist affiliated with a regional perinatal center or the medical director of the center. A list of the perinatal centers is in Appendix 4. If it is deemed appropriate and necessary, arrangements could be made for medical evaluation by someone from the perinatal center and/or the infant could be transferred to a perinatal center. Consent for either of these options should be sought from the parents.

13. If the worker, in consultation with the health care team, determines that current medical information on the infant's condition is not adequate to make a determination regarding the treatment questions and the parent(s) refuse consent for additional medical evaluation, the worker should seek court involvement to obtain permission to pursue additional medical evaluation.

14. If the CPS worker or agency find the need for further information or referral in locating medical or pediatric resources, a physician employed by the Wisconsin Department of Health and Family Services in Madison may be consulted by telephone. This person is knowledgeable about pediatric resources in Wisconsin and is generally available by telephone during working hours. If a message must be left make it clear that a Baby Doe case is involved and that your need is urgent. The person's name and phone number are: Richard Aronson, MD, Chief Medical Officer for Maternal Child Health, Bureau for Public Health, (608) 266-5818.

15. In some situations, it may be difficult to arrive at a unanimous opinion on the best way to proceed. It is sometimes impossible to ascertain when enough medical advice has been sought or how to handle differing medical opinions. Depending on the particular situation, seeking a wider range of medical opinions may or may not be helpful in arriving at a solution. The CPS agency, in concert with its consultants and advisors, will have to come to a resolution based on the best information currently available.

16. If informal resolution appears to be impossible, it may be helpful to seek consultation from the county corporation counsel or district attorney. If other avenues of resolution fail, it is appropriate to request that a petition be filed to use the authority of the court to assist in resolution. If court action is necessary, a petition can be filed under s. 48.13 of the

Wisconsin statutes alleging that the child is neglected. If an additional medical examination is sought, it can be ordered by the court under s. 48.295 following the filing of the petition. If immediate medical treatment is necessary, a petition for temporary guardianship can be filed under Chapter 880.

17. During the phases of the investigation that resolutions are being worked on, CPS should continue to be available to assess the needs of individual family members and to provide supportive services or referral as appropriate.

RESOLUTION POSSIBILITIES

The following resolution possibilities are presented for CPS agencies to consider when anticipating how to manage a Baby Doe report and guide the case toward satisfactory resolution. The resolution possibilities presented here should by seen as part of an ongoing process of the investigation.

1. Informal, nonjudicial resolution should be sought and, if at all possible, accomplished.

2. Movement toward resolution of a Baby Doe case may occur if, through careful investigation by CPS, it is ascertained that:

   - medically indicated treatment is in fact not being withheld
   - treatment is not medically indicated
   - medical neglect is not occurring
   - the current level of medical treatment has been reviewed by prudent physicians who are "knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved "(see definition regarding "reasonable medical judgement" p. 5) and is considered the appropriate treatment of choice by the treating physicians and by the parent(s)
   - an internal hospital review is in process, including seeking additional medical review and ethics committee consultation, which leads to an appropriate resolution
   - treatment is medically indicated, parents refuse consent, but with further information, support, and counseling agree to treatment
   - treatment is medically indicated, parents continue to refuse consent and court involvement is sought to obtain treatment
   - parents feel they cannot continue to make parental decisions regarding the infant, and, following intensive support and counseling, are referred to an agency for help in termination of parental rights and arranging for adoptive placement
   - parents desire additional medical treatment that cannot be obtained in the current setting and seek other medical resources

3. Resolution of a case means the end of the acute Baby Doe crisis, but not necessarily the end of social service contact with the family. Ongoing support, information, or referral may be appropriate.

APPENDIX 1

RESPONSIBILITIES OF A BABY DOE HOSPITAL DESIGNEE

A hospital designee is a person(s) who is designated by the administrator of each hospital that provides obstetrical and/or newborn services in the state. The designee's role is to provide coordination and consultation to CPS within the health care facility during a Baby Doe investigation. In addition, the designee has the following responsibilities:

- is familiar with the federal Baby Doe law, the State of Wisconsin Child Abuse and Neglect laws, and CPS procedures for investigating reports of medical neglect,

- is required to report to the local county child protective service (CPS) agency instances that come to his/her attention of medical neglect of a disabled infant,

- is available to receive inquiries from and provide assistance to the local county CPS agency in regard to a report received by that agency of a potential Baby Doe situation at the designee's hospital,

- facilitate a prompt assessment by a CPS worker, with the goals if minimizing disruption to the family of the infant in question and of hospital activities,

- is able to supply CPS worker with immediate information on the health status and treatment plan of an infant on whom a report has been received,

- is able to provide assistance to the CPS worker and any consultants involved in the CPS investigation, including talking with parents and physicians, contact with hospital ethics committee and/or reviewing its report, obtaining access to medical records and other pertinent reports, and obtaining necessary consent forms, and

- arranges for periodic in-service/educational/information sharing programs within the hospital for relevant physicians, nurses, social workers, and others who may potentially be involved in Baby Doe cases.

APPENDIX 2[1]

Part A

INFORMATION NEEDED FOR CPS ASSESSMENT OF CHILD'S STATUS

Is the child at the hospital?
What is the child's age?
What are the child's diagnoses?
Is the child's life endangered?
What is the life or health-threatening problem requiring treatment?
Are immediate actions necessary to keep the child alive?
Has withholding of life-sustaining treatment been recommended?
Has withholding of life-sustaining treatment been implemented?
Have the parents refused consent to life-sustaining treatment?
Will the hospital choose to sustain life-supporting care for the immediate future (24 to 72) hours while the CPS investigation is underway?
Is sustenance (food or water, whether given orally or through an intravenous or nasogastric tube) or medication being denied?
If so, on what basis?
What precisely, is the treatment (necessary for the child's life or health) that is being denied?
What treatment or sustenance, if any, *is* being provided the child?
How certain are the medical diagnoses among the treatment team?
Is there unanimity among treating physicians and consultants about treatment and diagnosis?
Have there been any other opinions, and what are they?
Who have been consulted and what are their qualifications?
What are the conclusions of the consultants?
If there has been consultation, did it include an examination of the child?
Who has discussed the case with the parents? What are the proposed treatments?
Who has proposed them?
What is the prognosis without the proposed treatments?
What is the prognosis with the proposed treatments?
What is the complexity, risk and novelty of the proposed treatments?
What is the clarity of professional opinion as to what is standard and accepted practice?
Has a hospital review process taken place?
What was the review process?
What were its recommendations?
Is treatment medically indicated?
Who, if anyone, has concluded that:

the child is irreversibly and chronically comatose? the provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infants life threatening condition, or otherwise be futile in terms of the survival of the infant?, or the provision of such treatment would by virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane?

Part B

INFORMATION NEEDED TO ASSESS PARENTAL DECISION-MAKING

Is there one or two parents of record?
If two, do they agree on the course of action to be followed?
Has the responsible physician recommended treatment for which the parent(s) have refused consent?
Were the parent(s) presented with all treatment options?
Was information about treatment options and the prognosis of the child withheld from the parent(s) or presented to them in an incomplete form or in a misleadingly pessimistic light?
Did the parent(s) understand the information?
What was the nature and degree of parental involvement in the decision to deny treatment or sustenance?
What is the parent(s)' view of the child's problems?
What are the parent(s)' major concerns for their child?
Do the parent(s) feel that they are being asked to consent to treatment which is inhumane?
What is the basis of the parent(s)' refusal to consent to treatment?
Have appropriate counseling services been made available to them?
Were the parent(s) provided information to facilitate access to services furnished by parent support groups, and public and private agencies concerned with resources for disabled persons and their families?
Were the parent(s) provided an opportunity to speak with other parents if children with similar conditions?
Did the parent(s) participate in or have access to the results of the hospital review process?
Would the parent(s) agree to consultation with the hospital review committee?
If they will not agree to treatment, are the parents likely to relinquish custody of the child?

Part C

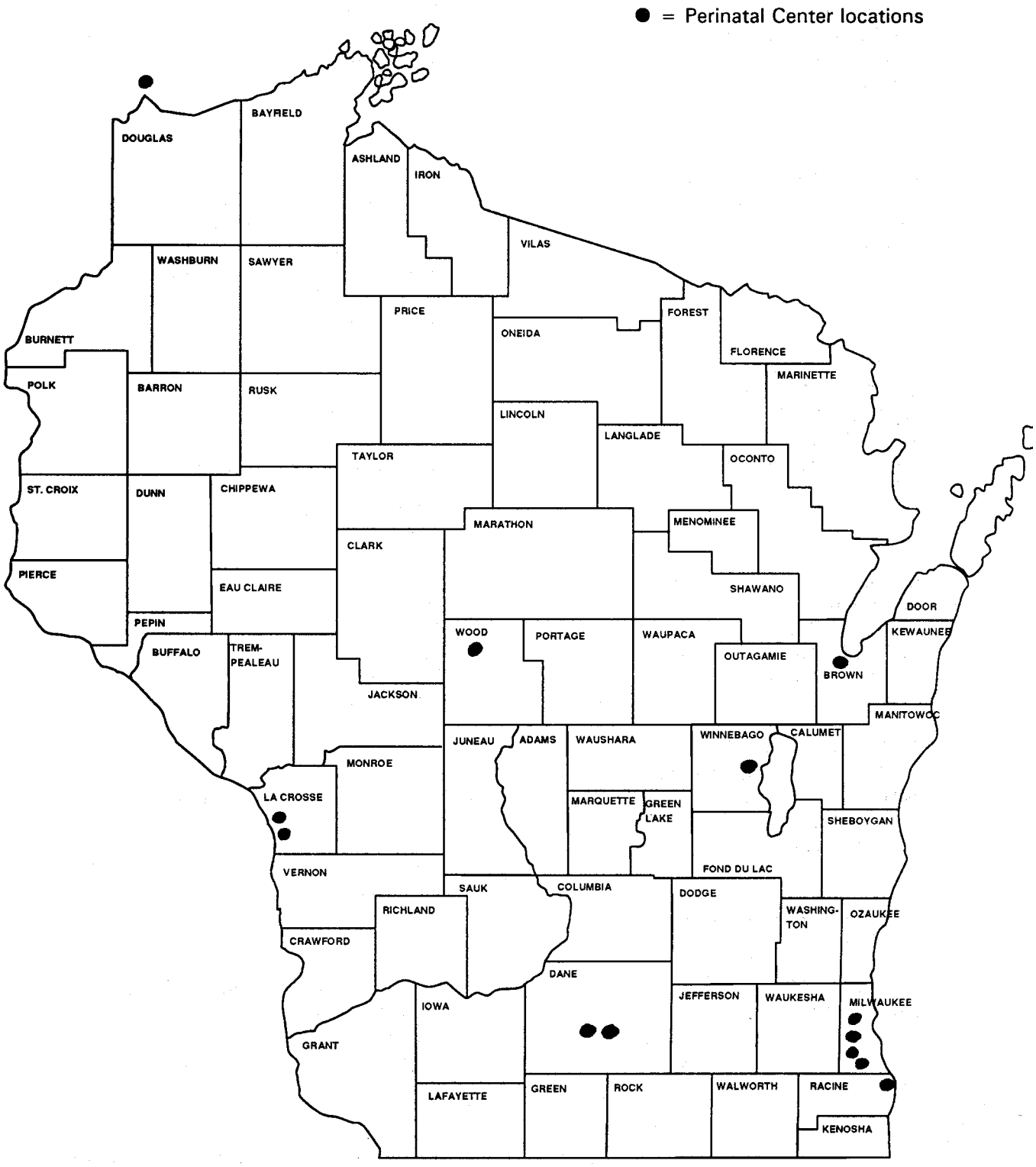
INFORMATION NEEDED TO ASSESS HOSPITAL REVIEW COMMITTEE ACTIONS

Is there a. hospital review committee?
Did the HRC verify the diagnosis?
Were all the facts explained to the parent(s)?
Were alternatives explored with the parent(s)?
Did the parent(s) appear at the meeting and have the opportunity to articulate their objections about treatment before the committee?
Were all the relevant facts before the committee?
Did all physicians, nurses and others involved in treatment have an opportunity to present information to the committee?
Was there any significant disagreement among committee members (and/or medical staff)?
What was this disagreement?
Was the committee recommendation consistent with the terms of "withholding of medically indicated treatment"?

[1] MODEL PROCEDURES For Child Protective Service Agencies Responding to Reports of Withholding Medically Indicated Treatment from Disabled infants with Life-threatening Conditon, by E. Bruce Nicholson, produced by the American Bar Assn., Commission on the Metnally Disabled and the National Legal Resource Cente for Child Advocacy andProtection.

APPENDIX 3

Map with Perinatal Center Locations.



See next page for names, address and phone numbers of Perinatal Centers

APPENDIX 4

PERINATAL CENTER ADDRESS AND TELEPHONE NUMBERS - WISCONSIN

St. Francis Medical Center
700 West Avenue, South
LaCrosse, WI 54601
608-785-0940
Ask for IICU

LaCrosse Lutheran Hospital
1910 South Avenue
La Crosse, WI 54601
608-785-0530
Ask for Nursery

Meriter Hospital
202 South Park Street
Madison, WI 53715
608-267-6000
Ask for Special Care
Nursery

St. Mary's Hospital Medical Center
707 South Mills Street
Madison, WI 53715
608-251-6100
Ask for Neonatology

St. Joseph's Hospital
5000 West Chambers Street
Milwaukee, WI 53210
414-447-2000
Ask for Neonatology

St. Mary's Medical Center
407 East Third Street
Duluth, MN 55805
218-726-4000
Ask for NICU

Children's Hospital of Wisconsin
9000 West Wisconsin Avenue
P. 0. Box 1997
Milwaukee, WI 53226
414-266-2000
Ask for Neonatology

Sinai Samaritan Medical Center
2000 West Kilbourn Avenue
P. 0. Box 342
Milwaukee, WI 53201-0342
414-345-3400
Ask for Neonatology

St. Vincent Hospital
835 South Van Buren Street
Green Bay, WI 54307-3508,
414-443-0111
Ask for Perinatal Services

St. Joseph's Hospital
611 St. Joseph's Avenue
Marshfield, WI 54449
715-387-1713
Ask for NICU

Theda Clark Regional Medical Center
130 Second Street
Neenah, WI 54956
414-729-3100
Ask for NICU

All Saints Health Care System, Inc.
1320 Wisconsin Avenue
Racine, WI 53403
414-636-2011